

Understanding Brain Stem Glioma

(SE) Chris Ryan November 02, 2010



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Brain stem glioma is supposedly a type of cancer which is generally found in children and teenagers. The normal cells in the brain multiply uncontrollably and thus form a mass of tumor. A tumor can be either malignant tumor or benign tumor. Glioma is the tumor which affects the glial cell that is a supportive cell in the brain. Brain stem glioma is known to spread rapidly through the brain stem during the process of diagnosis. This type of tumor is known to be aggressive as it spreads quickly. This type of tumor largely affects children who belong to the age group of five and ten years old. Brain stem glioma is a life threatening disorder mainly because it grows in the part of brain stem where it is difficult to perform a surgery.

This type of brainstem cancer affects the cranial nerves, the cranial nerves are the ones which supply the muscles connected to the eye, face and the muscles which are involved in swallowing. Thus the symptoms comprise double-vision, incapability to close eyelids properly, tilting a particular side of the face, and complicates the procedure of chewing and gulping down. This tumor even hampers the process of walking and speaking. Symptoms rapidly worsen as and when the tumor grows. These tumors also obstruct the cerebrospinal fluid in the brain this increases the frequency of vomiting and headaches.

For effective treatment of brain stem glioma radiation is the best suggested alternative. Surgery is mostly not conducted because these tumors are extensively spread within the brain stem. A number patients have to face permanent psychological, cognitive and defects which arise from the treatment itself. Around 3,800 children suffer from brain stem glioma annually and around 950 of these are mostly benign tumors. It has also been estimated that only about 10 to 15 percent of the children who suffer from the brain stem glioma survive this disorder within three years of the diagnosis.

Cancer.im is the next-generation social networking and resource site for cancer patients, advocates, and volunteers. It boasts many of the features of existing social networking sites like Facebook or MySpace, such the ability of members to blog, post pictures and videos, make and remain in contact with friends, and find others with similar interests.

But unlike those other networks, Cancer.im was designed by [Dr. Mahesh Kanojia](#) a world famous oncologist and [Chris Ryan](#) a cancer advocate to specifically serve the unique needs of those currently struggling with the disease. This new network combines databases of medical community knowledge, repositories of wisdom from cancer survivors, systems for helping cancer patients organize their records and various facets of their treatment, and tools that allow patients and their supporters to work together effectively. In short, Cancer.im provides everything a cancer patient, friend, or family member is looking for to help in the fight against the disease, all in one online location and easy-to-use format.

The Vision and Goals of Cancer.im

The vision that led to the creation of Cancer.im was to increase cancer patients' Quality of Life (QOL). Research has shown what most people involved in cancer treatment have long known intuitively, that increasing patient QOL results in a drop in morbidity. One of the most important factors in improving QOL for a patient is having an active support network. Clinical studies have confirmed that those cancer patients with an active support network of friends, family and other advocates outlive those who do not. Cancer.im's networking tools empower every cancer patient to take

control of their treatment by giving them the tools to find, organize and manage their own cancer support network.

Empowering Through Support Networks

Friends, family, and other advocates are one of the most valuable support tools available to a cancer patient. Cancer.im allows patients to organize and empower their support network. For patients, this can mean something as simple as being able to send one email to communicate with their entire network, and as complex as scheduling supporters who have offered to provide food after chemotherapy sessions. On the side of patient friends and family, it is often difficult to know what help to offer or what to say to someone dealing with cancer. Feelings of helplessness can set in, and supporters can withdraw from a patient just when they are most needed. The networking tools provided by Cancer.im can be used to encourage supporters to remain active. They allow patients to communicate more effectively with their friends and family their current condition, their treatment progress and schedule, their needs, and their thanks. Support network members can know exactly how to contribute to a patient's well being, and the patient can avoid duplication of efforts among their advocates.

Empowering Through Increased Knowledge

There is an old proverb that says "knowledge is power." To further empower patients and thereby increase their QOL, a set of specific knowledge-building tools was developed to be a seamless part of Cancer.im. These knowledge-building tools make Cancer.im much more than a traditional online network consisting only of groups, event calendars, and personal profiles. These tools allow members to:

- * Learn from the wisdom of other cancer survivors through video clips;
- * Research all aspects of cancer;
- * Organize medical records, insurance, and research;
- * Create a customized treatment strategy based on education, beliefs, and resources; and
- * Develop a proactive cancer prevention strategy.

Patient Wisdom Video Clips

Get the power of hindsight with the timing of insight! Every cancer survivor has a unique story to tell. The hindsight and experiences of those who have already "been there" are invaluable to patients currently battling the disease. Members of the Cancer.im network can find survivors who have lived through a specific type and stage of cancer. They can learn from these survivors what to expect in the coming weeks and months, what behaviors helped their treatment, and what pitfalls they may have encountered. Members can even enlist someone who's already "been there" to become a personal mentor, or sponsor. Sponsors help cancer patients develop the good habits and break the bad habits that will help them in the course of their treatment.

Many cancer survivors find themselves burdened by having to repeat their stories several times, either to friends and family or to other cancer patients. Cancer.im enables survivors to record their stories for the benefit of future generations without having to personally repeat them. A standard set of interview questions has been developed that can be asked of every cancer survivor. Every answer to a question in the set results in a 30 to 60 second video clip. These clips then become part of a searchable database, or VIEW, which stands for Video Indexed Encapsulated Wisdom. The VIEW can be searched by the demographics of the survivor – their age and sex, for example – the type of cancer, and by any important keywords used in the video.

Cancer Research Database

Cancer patients, when they begin to research their disease, suddenly find themselves awash in a sea of information. Personal research can produce as many questions as it produces answers. This can create increased anxiety in cancer patients, make them feel confused, and generate a sense that they are losing control over the treatment of

their disease. To break this cycle Cancer.im has been amassing the largest Portal Indexed Cancer Research Database currently available online. This Portal Indexed Research Database was created to offer information on each of more than 62,000 different aspects of cancer research.

These aspects are not simply medical descriptions of types of cancer. They include treatment strategies, alternative medicines, clinics specializing in certain cancers or treatment approaches, oncologists and their specialties, recommended diets and exercise programs, and proven and experimental cancer prevention strategies. There are also entries in the database capturing patients' experiences with different doctors and medical centers, evaluating them not only from the perspective of results but also in terms of level and type of care.

Research volunteers formed into Micro Social Networks (MSNs) are tasked with helping Cancer.im members understand and research any and all of these different aspects of cancer. Network members can subscribe to receive information on cancer research and have a volunteer respond to their request with their findings.

Organizational Tools

As with any major life event, cancer brings paperwork. Patients can feel overwhelmed by the sheer quantity of health records, medical bills, insurance forms and claims to be filed for which they are now responsible. Treatment for cancer may also involve a major rethinking of home finances, since it may bring with it a loss of one or more income streams in addition to the new expenses of cancer treatment.

Cancer.im has partnered with two leading Electronic Health Record (EHR) companies to help every member organize their health information. Members who have all their health information just a few keystrokes away also have an increased sense of control over their treatment, a correspondingly higher sense of well-being, and lower anxiety. All health records stored with Cancer.im are kept under tight security and accessible only by the member.

The social networking aspect of Cancer.im can also help members with their financial needs, especially organizing and filing claims for health insurance and government assistance. Members may encounter difficulty working with insurance companies or in understanding their claims processes. Some may not know whether they qualify for Social Security assistance, or how to go about applying if they do. Volunteers and charitable organizations on the Cancer.im network are ready to provide direction and, if necessary, serve as advocates for the member with their insurance company or with government agencies. These advocacy individuals and groups have the experience of working with thousands of other cancer patients on these cases. Working with them can help a cancer patient understand that any paperwork problems they are encountering are not unique to them, and that they need not feel alone in dealing with them.

Cancer Mission Adaptive Plan (MAP)

On the road to recovery it is imperative for every cancer patient to remain proactive in their treatment, and maintain a sense of being in control. This is a critical aspect to maintaining a high Quality of Life. Cancer.im includes the tools to help patients develop their own Mission Adaptive Plan, or MAP. These MAPs are put together based on the input of oncologists and other cancer survivors and advocates. A MAP is a 16 step program of best practices which allows patients to craft a customized treatment strategy based on their own educated beliefs, values, and resources. Some of the steps that are part of the MAP creation process are:

- 1) Accepting the diagnosis of cancer, and realizing that dealing with it is more productive and healthier than denying it. While this may seem like an obvious step in the cancer treatment process, research has shown that it may be one of the most difficult to complete. The sooner cancer patients are able to accept their situation, the sooner they will be able to become involved in the treatment process.

- 2) Identifying and building a relationship with a Cancer.im sponsor. This sponsor will be someone who has already

been treated for the patient's form of cancer, and who can help them walk through the treatment process. The friends and family of a cancer patient may know them best as persons, and be able to offer moral support. But a sponsor can share the experiences associated with being treated for the cancer itself.

3) Finding an oncologist, treatment center, or clinic, using a database complete with ratings and reviews from other cancer survivors. Who better to evaluate the level of care and competency of a doctor or center than one who has already used their services?

4) Help adopting an exercise program appropriate to the member's treatment regimen, and assistance in creating a healthy diet with the nutrients necessary to counterbalance the treatment being undergone.

5) Researching medications and evaluating them for interactions. Negative drug interactions cause more than 100,000 deaths in the United States each year, ranking as the 4th highest cause of death. Cancer.im encourages members to register the medications they are on, and provides the tools necessary to evaluate them for adverse interactions.

6) Encouragement for members to become Cancer.im sponsors themselves, and share their insights and wisdom in the form of video interviews.

Printable MAP

Cancer.im realizes not all members will have a computer or know how to use one. The MAP is broken down into 16 printable sections, each of which represents step. Now cancer patients can take their research findings to doctors' appointments for explanation, or read new research at their leisure apart from a computer screen. Members of a patient's support network who are computer literate may help them develop their own MAP and print it. These same advocates may be encouraged to create their own MPA as a proactive cancer prevention strategy.

Conclusion

www.Cancer.im is more than just another social network. It provides all the tools necessary for cancer patients to maintain a high Quality of Life during treatment, and maintain a strong network of supporters. Cancer.im enables members to remain organized, informed, and empowered patients. The network's ultimate goal is, by all these means, to maximize every patient's opportunity to become a cancer survivor